

# The University of Bradford Institutional Repository

<http://bradscholars.brad.ac.uk>

This work is made available online in accordance with publisher policies. Please refer to the repository record for this item and our Policy Document available from the repository home page for further information.

To see the final version of this work please visit the publisher's website. Available access to the published online version may require a subscription.

**Link to Publisher's version:** <http://www.routledge.com/9781138949935>

**Citation:** Small N, Fermor K, Mir G and Members of the HOPE Group (2016) Inequality, exclusion and infant mortality: listening to bereaved mothers. In: Harris D and Bordere T (Eds) Handbook of Social Justice in Loss and Grief. New York: Routledge. pp 50-63.

**Copyright statement:** © 2016 Routledge. Reproduced in accordance with the publisher's self-archiving policy. This is an Accepted Manuscript of a book chapter published by Routledge in Handbook of Social Justice in Loss and Grief, 2016. Available online: <http://www.routledge.com/9781138949935>.

**Title.**

**Inequality, exclusion and infant mortality: listening to bereaved mothers.**

**Authors.**

Neil Small, Katie Fermor, Ghazala Mir, and members of the HOPE group.

Further details.

Dr Neil Small, Professor of Health Research, School of Health Studies, University of Bradford,

Richmond Road, Bradford UK BD7 1DP

[n.a.small@bradford.ac.uk](mailto:n.a.small@bradford.ac.uk)

Dr Katie Fermor MBBS MRCGP DFRH MSc.

Spectrum Community Health, 15 Margaret Street, Wakefield WF1 2DQ

Katie.fermor@spectrum-cic.nhs.uk

Dr Ghazala Mir.

Associate Professor, Leeds Institute for Health Sciences, Charles Thackrah Building 101

Clarendon Road. Leeds UK LS2 9LJ

[g.mir@leeds.ac.uk](mailto:g.mir@leeds.ac.uk)

HOPE-Leeds and HOPE-Bradford are groups made up of women from these two UK cities who have experienced the death of an infant.

Corresponding author: GhazalaMir

(address + email above)

Word count: (including title page and references) 6536

## **Inequality, exclusion and infant mortality: listening to bereaved mothers.**

### **Introduction**

This chapter will examine issues of social justice by focussing on social exclusion and infant mortality. Infant mortality is defined as the death of a live born child before its first birthday. Social exclusion and infant mortality are both important areas of policy debate in the UK and globally<sup>1</sup>. We will examine how far they are linked and will focus on ethnic minority populations with higher than average rates of infant mortality. The chapter continues by considering a small group of women who have experienced the death of an infant and who have come together in a group called HOPE. We ask how their experience might inform our understanding of the needs of women at the time of childbirth and in the weeks immediately following it. Their experiences illuminate how feelings of exclusion, and injustice, can be manifest in and through the structures and processes of engaging with health care professionals. The potential to promote social justice and enhance inclusion via listening to the voices of those who have had this experience of loss is considered.

### **Structural and behavioural influences on infant mortality.**

The UK's National Perinatal Epidemiology Unit has identified three main factors; the direct effects of poverty, variations in behaviour and differential access to services, as combining to cause persistent and wide inequalities in pregnancy outcomes and in the health of babies.<sup>2</sup> More specifically, infant mortality rates in the general population are strongly associated with the social position of women.<sup>3</sup> Women's levels of education and literacy, their socio-economic status and the level of relative deprivation in their area of residence are all correlated with the risk that their baby will die in its first year<sup>4</sup>. This pattern is observed world wide<sup>5</sup>. Infant mortality is also consistently associated with birth weight and pre-term birth, mother's age, birth spacing, with

access to a range of maternal health technologies and with lifestyle characteristics of the mother and her household. Most notable ‘behavioural’ risk factors that will affect significant numbers of women in the UK are smoking during pregnancy and poor nutritional status. There is a complex interchange between the behavioural and structural influencing infant mortality. Smoking rates during pregnancy are higher in women who are more socio-economically deprived, and poor nutritional status is also more evident in deprived groups.<sup>6,7,8.</sup>

Just as there is a close correlation between key behavioural influences and structural inequalities so there are complex associations between different structural dimensions of a person’s life. Socio-economic background and ethnicity are separately associated with poor birth outcomes<sup>9</sup>. However there is a close association between these two factors. Infant mortality rates are higher in local authority areas with the highest deprivation indicators. These are also the areas where minority ethnic communities are over-represented<sup>1</sup>.A further compounding of the structural and behavioral is evidenced in relation to higher than average rates of infant mortality in babies born to teenage mothers. Levels of deprivation are high in most minority ethnic groups and are high for teenage mothers. In some, but not all, minority ethnic groups rates of teenage pregnancy are higher than average, for example rates in Caribbean communities are higher and in Pakistani origin communities are lower <sup>1</sup>(see Fig 1).

Fig 1.

<u>Rates of infant death in England and Wales</u> (recorded as death of live born infants before age 1 per 1000 live births) <sup>4</sup>		
National rate 4.2		
	<i>Rate</i>	<i>Rate Higher by</i>
Caribbean mothers	9.7	131%

Pakistani mothers	7.6	81%
W. African mothers	7.4	76%
Teenage mothers	5.4	29%

In addition to both structural and behavioural influences on maternal health and on infant mortality the configuration of health services can also exert a powerful influence. Improvements in care during pregnancy, labour, and birth significantly affect the health outcomes of mothers<sup>10,11,12</sup>. But improvements to these services, as currently configured, while impacting on maternal health outcomes may not reduce health inequalities unless services are tailored to meet the specific needs of disadvantaged women. Likewise risk reduction strategies and public health interventions, such as addressing environmental stressors or health education services advising on behavioural change, disproportionately benefit those who already occupy advantageous social positions. As with service provision, these strategies need to be targeted and reconfigured if they are to specifically benefit disadvantaged groups and hence impact on health inequalities<sup>13</sup>.

While there are strong similarities in the patterns and prevalence of structural and behavioural factors impacting on infant mortality and maternal health at the time of birth there are also some factors that are likely to have a greater impact on a smaller group of mothers. These are factors that do not affect the generality of mothers and babies but those they do affect they affect profoundly. For example maternal diabetes or HIV positive status, or the use of non-prescribed drugs during pregnancy, exert a high risk for the babies of women with these characteristics . A further example is that there is a genetic contribution to infant mortality. This is evident in all sections of the population but affects the Pakistani population to a greater extent and is linked to the increased risk for families in communities who favour consanguineous partnerships.

Consanguineous couples affected by a genetic condition have a higher incidence of babies born with congenital anomalies, some of which may be lethal<sup>14</sup>.

### **Social networks and maternal and infant health**

The development of research on the impact of social capital on health<sup>15</sup>, on ethnic density as potentially both a health promoting and health limiting phenomena<sup>16</sup> and on the significance of the extent of inequality in any society rather than the absolute level of deprivation<sup>17</sup> complement, more established analytic categories including poverty and ethnicity in the study of health experiences..

There is now an extensive body of literature on social capital providing evidence that both a persons' social environment and their networks impact on health outcomes both through psychosocial and physical mechanisms<sup>18,19,20,21</sup>. The ability to 'bond' with those inside and 'bridge' to those outside one's social group increases access to resources at both personal and community levels. High levels of 'bridging', social interaction between diverse social groups, increase social cohesion<sup>15</sup>, which, in itself, is a positive determinant of health.

At a community level such interaction can influence health outcomes through promoting healthy norms of behaviour, restricting unhealthy behaviours and diffusing health information. Socially isolated individuals are more likely to have poor health outcomes and be located in communities that are depleted in social capital. Both stress and self-esteem impact on social relations and physical wellbeing<sup>17</sup>.

But, as with the relationship between structural and behavioural influences on health, socioeconomic status is a key factor mediating the effects of social networks. Access to material resources and

contacts promoting health and wellbeing are facilitated and sustained in networks within economically advantaged communities and a “network of poverty and disadvantage” can perpetuate inequality<sup>22</sup>.

### **Social networks and minority ethnic communities.**

Being part of a minority ethnic group and sharing culture and social support networks may be protective of one's health, even in economically deprived contexts. This is illustrated by research in the USA on the “Latina paradox”<sup>23</sup>. Latina women have comparable birth outcomes to white women of better socioeconomic status. McGlade et al argue that this is because systems of family, friends, community members and lay health workers provide support. However, the same effect was not observed for Black mothers, for whom living in an area of moderate to high same ethnic density was associated with a higher risk of low birth weight, preterm birth and infant mortality<sup>24</sup>.

There has also been concern that racism, a persistent feature in the lives of women from minority ethnic communities, was especially evident during pregnancy, for example in assumptions made by health care workers that led to them not acknowledging reported pain<sup>25</sup>. The 2010 National Perinatal Epidemiology Unit highlighted how women from minority ethnic groups had their first antenatal contact later than the general population. Other studies have reported less awareness of choices around maternity care, less trust and confidence in staff during labour and birth, and less satisfaction with communication from staff<sup>26</sup>. Similar findings were obtained by the Healthcare Commission, women from minority ethnic groups were more likely to be left alone during labour and reported feeling worried by this. This may be because health care professionals feel poorly equipped to communicate effectively with patients from Black and Minority Ethnic groups. Chevannes, looking at training needs, identified shortcomings in addressing the needs of women from these groups, apart from dealing with particular conditions such as sickle cell anaemia<sup>27</sup>.

### **Social support, birth and postnatal mental health.**

There are specific aspects of social support that are of increased importance around the time of birth. Notwithstanding the contribution of social networks, introduced above, many studies show the significance of partners for a woman's sense of well-being, sometimes this is positive sometimes negative. In a UK study only a few young women with a supportive partner, reported feeling unhappy since the birth, compared with two thirds of those with no supportive partner<sup>10</sup>. There is significant evidence that a lack of social support is a risk factor for post natal depression<sup>20</sup>. Essex and Pickett found that women who did not have a companion at birth were more likely to have their baby admitted to the neonatal ward and for the baby to have a low birth weight<sup>28</sup>. Conversely, the presence of a friendly companion during labour reduces birth complications<sup>11</sup>. Pakistani and Black mothers and women from non English speaking households and deprived households were more likely to deliver alone<sup>29</sup>.

Husbands and male relatives may also be significant in influencing engagement of women with antenatal groups<sup>30</sup>. But strong family ties might also impact negatively on take-up of care. St Clair et al found that stronger family ties among inner city, low income, women in the US were associated with "underutilising" prenatal care<sup>31</sup>. Perhaps the bonding associated with these family ties deflects investment in bridging between mothers and health care providers. Further, strong ties can also be problematic. Conflict, stress and a resulting absence of help can all result from close relationships, and the *presence* of these negative relationships are more predictive of depression than is a *lack* of supportive relationships. There is also a distinction between perceived and received social support. It is perceived support which is most closely tied to health outcomes<sup>20,12</sup>.



## **Supporting women to have their say**

This literature on aspects of inequality in the experience of giving birth and in relation to infant health suggests that a complex interchange between structural factors, social networks, behaviours and interactions with care providers shape experiences. We now turn to reporting the views of women who were recruited to a research study funded by the UK's Economic and Social Research Council (ESRC) and undertaken between December 2010 and December 2013<sup>1</sup>.

This study sought to explore the nature of social networks and consider how far they contribute to maternal and child health for women from diverse communities. The study also provided an opportunity for women who had experienced an infant death to suggest interventions they felt would improve care and then to consider how effectively these suggestions could be translated into practice. It is this second objective that we focus on.

The study was conducted in the cities of Bradford and Leeds in the North of England. They have higher rates of infant mortality than the national average and are both multi-ethnic cities with areas of considerable deprivation. Interviews were undertaken with 23 women who were from African or Pakistani backgrounds or who were teenagers and who had experienced an infant death as well as 26 women from a range of ethnic backgrounds and ages who had felt well supported throughout pregnancy and the first year of their child's life. Women who were interviewed were offered the opportunity to participate in a further participatory phase of the research centred on the establishment of two project development groups aimed at exploring solutions to the problems identified in interviews. Of the 23 bereaved women who took part in the study, 10 took part in the participatory phase, four at one site and six at the other. Women were keen to meet regularly in the groups they named 'HOPE' (derived from the acronym for Healing, Opportunity,

---

<sup>1</sup> ESRC Grant number RES-061-25-0509. Views expressed here are the authors and not the ESRC's.

Peace and Emotion), motivated by the desire both for mutual support and to make a difference for other women and families in the future. Group members had training and support to develop ideas about service changes that were needed, and to engage with key local professionals.

### Accounts from HOPE members.

Members wrote about their experiences and we present summaries from six of them here. These summaries identify events linked to their child's death. They offer suggestions for change and they also address the positive results they attribute to their involvement in HOPE, both for themselves and for others.

**Rezvana:** being listened to

#### My experience.

*Being listened to:* I am very grateful to the NHS for everything they do. However through my journey of the hospitals I noted that 'being listened to' is a key factor, but not implemented.

*Need for sensitivity:* I have lost two sons: Hashim seven years ago and Haider Ali just over a year ago.

My planned Caesarean section for Haider was on the date of Hashim's death anniversary. I explained this to the consultant. How could I celebrate one son's birthday on the date of my other son's death anniversary? But that didn't matter. I had to have the Caesarean.

#### What needs to change?

*Listen and then act:* The doctors said my son was ready for discharge even with a chest infection. I explained I had not slept for two days, I had no support on the weekend but even then they stood by their decision. Listening to the concerns is not enough. They need to be acted on. It's hard enough for parents to lay-out their fears without feeling like they don't

matter. Why listen if you're not going to do anything about it?

Being part of HOPE

I have become a member of the Maternity Services Liaison Committee (MSLC) since joining HOPE, and want to be able to influence decisions about maternity care for women in the city. I raised my point about listening and acting at the MSLC meeting and expressed my concerns as a parent. I hope that changes will be made as a result of this.

**Naz:** delays in admissions.

My experience.

*Listening to mothers:* Unfortunately in 2008 my third baby Uzair passed away with Congenital Myopathy. About 5 or 6 weeks before he was due, I rang the hospital delivery suite at 9 am and said I was having sharp pains. I could tell it was labour because I'd had a baby before. They said "Oh, stay at home, you're not ready, take pain killers". A few hours later I rang the hospital again and they said "take pain killers". We went to the hospital ourselves about 5pm. By 6.15pm they had to rush me and then they started panicking. They had to rush me to delivery through the corridors into the delivery suite when I delivered Uzair. This also happened to me in 2001 when I had my daughter Elesha, they wouldn't admit me when I knew I was in labour, I wanted to be in hospital.

*Being involved in care:* When Uzair was born, I knew that he was not going to be with me forever. It was so difficult for me and my husband but we wanted to do everything for our son and make him comfortable. With the supervision from the staff in the neonatal department, I was able to write up the feed charts and medicine charts and have a good cross-infection control around my son's cot area, writing up diaries and keeping daily records. Memories are the best things you can have once you have had the loss. If I look back, I don't

regret for one minute that I didn't do anything for him, I did everything as I would do at home, whatever I could do.

What needs to change.

Regarding admissions - I feel that the staff should listen to Mums because they know their body best. The staff should let the Mums come in for an assessment and be reassured. I feel that parents should be encouraged to do more for the baby than sitting and watching and feeling lonely, especially when the child has a short time to live.

Being part of HOPE.

*For others:* HOPE group is working to make some changes: we have met with a Consultant Midwife to discuss problems with admissions, who will report back to the group. We met with a Neonatal Consultant and will become members of a service user group for the Neonatal Unit. We worked to get diaries printed by the Neonatal Unit for parents with sick children. Through HOPE we have been able to learn about, and work with, lots of local and national organisations like BRI, Health Visiting, befriender training with SANDS, and BLISS\* for parent support.

*For myself:* I feel like a stronger person and not afraid to speak up. I've had my voice heard at conferences and been able to take a lead role. I've enjoyed doing things that will help other parents to get support that we didn't get. HOPE is like a team where everyone supports each other and we make joint decisions.

*\*BRI is the local hospital, SANDS and BLISS are national charities (SANDS – Stillbirth and neonatal death charity: BLISS – for babies born too soon, too small, too sick.)*

**Nazreen:** genetics.

My experience.

After my daughter Mariam died, I was told several times that it's because I'm married to my cousin, this is why my daughter was ill. This was really upsetting and shocking to me. When I was marrying my husband we didn't have the intention of having disabled children. There were lots of reasons, apart from children, that we chose each other. It's not our fault – in no way would I want to lose a child. Please don't judge me because I'm married to my cousin. I've had three beautiful baby boys and we've had enough losing a daughter. It doesn't help to be blamed for something that I didn't even know about.

What needs to change.

*Knowledge and sensitivity:* Children can have genetic conditions for lots of different reasons, for example having children when you are older. Sometimes nobody knows for sure what the cause is. It's important to find some kind of way to do tests and find out why this has happened. But don't blame us for something that we didn't even want to happen to us.

Being part of the HOPE

*It's helped me:* The group has helped me understand this issue more and that I should not be blamed.

*Helping others:* In the HOPE group we are talking to people who work in the NHS. Some of the group are members of the Maternity Services Liaison Committee that makes decisions about how maternity services are run.

**Ansa:** discrimination / quality of care.

My experience.

*Racism:* I have had both negative and positive experiences, in terms of interaction with hospital and community professionals. During labour when I was losing my daughter Mariam

the midwife made insensitive, derogatory and racist comments to me and my husband. There was no interpreter offered to us, so I had to translate what was happening for my husband when I was trying to come to terms with it myself. There was also no counselling available in our mother tongue.

*Ill-timed insensitive care:* Two weeks after the loss of my son Tariq, community midwives came to my door asking to weigh my baby, it was a painful heart-wrenching experience, and very distressing for my husband also.

*Knowing about risk factors:* Antenatal classes are tailored to normal pregnancies and don't give you any information about risk factors or what to do when things don't go well. After I lost two babies a consultant started looking at my case in detail and the problem with my pregnancies was identified and dealt with. I am really grateful that this happened but I feel these issues could have been picked up before I lost Mariam. I now have my son Mustafah who is 9 months old. The care provided throughout my pregnancy was outstanding; I was treated with respect and dignity.

#### What needs to change

*Improvements needed:* I would like a referral to be made to a support service as soon as it is established that a woman is going to lose, or has lost, a child. There is a need for support to liaise between families and professionals and advocate for women, to promote good mental and physical health following a loss. This needs to be consistent across the board. In HOPE we are working with the MSLC to improve the bereavement support pathway, and we will have befriender training ourselves. Counselling should be available in other languages and I am looking into training for this myself.

#### Being part of HOPE

*Working for others:* The HOPE group is working with Public Health professionals to adapt the "Pregnancy, Birth and Beyond" antenatal programme. We are also aiming to set up a

specific antenatal support group for women who have experienced an infant death. The voice of HOPE members has led the Maternity Services Liaison Committee to create a subgroup to improve the bereavement support pathway, using SANDS guidelines.

*Changes for me:* A journey of many revelations of my own self-awareness, strengthening of my own resolve and becoming very motivated to help other bereaving parents even more by empowering them with the right information, which I have come to learn of through HOPE.

A great opportunity to meet other bereaved mothers and have a support group, a safe and open place where I could share my experiences, feelings and thoughts on improvements needed for the maternity services currently provided in Leeds. The research group

empowered me to be motivated to set up a support HOPE group for bereaved parents

I have also now enrolled on a Professional Counselling course to further my career in helping others which I have done for many years in my various voluntary roles in my community

Introduced to community groups and providing contacts such as the MSLC and SANDS.

**Shabana:** feeling isolated.

My experience.

I felt isolated after my emergency C-section and after my twins passed away. I was placed at the end of the ward right at the end of the corridor and I didn't get any support from the midwives. They didn't really come to my room much. I felt isolated and a bit angry, all of these mixed emotions. The only support was from my family that came to visit me. I think the hardest thing is leaving the hospital with no baby, and at one point I felt like I wouldn't be able to. I think women need support then.

What needs to change

*Support:* The thing I'd change is to give more support to those women who are going through

a bereavement. If a midwife could come downstairs with you when you leave hospital - just a little support would make a big difference

Being part of HOPE.

*For myself:* More confidence as I was a shy person. Support from other people from the group . Help to deal with the loss and bereavement. Knowing/feeling I can make my voice heard.

*Support from and for others:* Being involved with the HOPE group has enabled me to meet other women going through similar experiences, helping us in some way to deal with our loss. One thing we are doing is working with health visitors and midwives to create a support pathway for women who have lost a child.

**Kim:** lack of timely care.

My experience.

*Delays seeing GP:* I lost Ashley on 16th December 2004 due to an infection called staphylococcus, which was white spots around the genital area. I was given something by my midwife, like white powder, to use. I tried to make a GP appointment on the Monday but no appointment was available until the following Monday. He passed away the Thursday of that week. He would have been 9 years of age this year. It was especially hard as it was the Christmas period.

*No care after the death:* After my son Ashley passed away, no support or counselling were offered. I did not receive my postnatal check-up, which could have led to depression. I only received one leaflet. All I needed was someone to speak to. I wasn't happy with the overall experience.

*Other positive experiences:* My first two pregnancies were straightforward and very positive. The hospital was supportive as they knew I was a young mum at the age of 17. My labours



were great with no complications. Then I went on to have two more healthy pregnancies, Katelyn and Jayden which, again, were positive experiences.

What needs to change

In the future I would like to see more bereavement groups, a place where children, siblings and family members can talk about their loss. More support in hospitals, more distribution of leaflets and overall a buddy system.

Being part of HOPE

Since I came to the HOPE group I have come a long way, I have come out of my shell because of all the support from mums in the group and the professional help from the team.

The HOPE groups identified key priorities for action and produced documents outlining their ideas for what would help. Key priorities were identified in the areas of relationships, knowledge and service design. Women at both sites wanted to be listened to and taken seriously by professionals, not to feel judged or stereotyped, and to have access to more bereavement support. In addition, being better informed about warning signs and having honest, clear and complete information were seen as priorities for improving the quality of services. In terms of service design, women at both sites wanted more involvement in decisions around how services are run. Better interpreting provision, more resources in other languages, a better ethnic mix of staff and targeted support for women most at risk were additional priority areas identified. As well as issues relating to health services members of HOPE also explored other areas where they reported insensitivity and injustice. These related to the social care and criminal justice systems. Group members Cecelia and Shameem argued that it was important that mothers felt supported within these broader encounters following the loss of an infant.

HOPE members were involved in presenting findings about what they saw as gaps in support at two developmental workshops attended by local practitioners and policymakers and designed to stimulate service development. They also presented their thoughts, alongside summaries from the research team, at two conferences, one in Northern Ireland and one in northern England. Other dissemination activities involved group members in media presentations including TV.

### Evidence of impact.

At both sites, HOPE members formed links with the Maternity Services Liaison Committee, including involvement in an MSLC subgroup tasked with improving bereavement support at the local hospital trust. They also worked with Public Health to tailor antenatal education material for women in higher risk groups. In one city a health visiting/ midwifery pathway for women at higher risk was developed and also a neonatal service user forum. Initiatives on interpreting provision, staff diversity and identifying women at higher risk in delivery-suite triage were also developed.

As is evident in HOPE members accounts some of the experiences and perspectives presented could be hard for professionals to hear, but those who did engage focused on drawing out lessons and on solutions rather than taking criticism personally. Some HOPE members found it frustrating that change was slow to happen and that more had not been achieved. But when they felt local practitioners engaged with them there was more of a sense of tangible achievements.

Evaluation of the participatory phase of the research study showed that women who took part appreciated the opportunity to be more involved in the research. All felt that they had been able to have a say in developing the aims and direction of the study. The conferences and the developmental workshops were felt to have been very successful and worthwhile and while public

presentation and telling one's story to the media were challenging they were also felt to be worthwhile.

As well as access to professionals afforded in the conferences and workshops and the evidence of local impact in terms of service changes the work of HOPE has been recognised at a national level. In 2012 the policy debate in the UK featured a significant intervention, via the Chief Medical Officers Annual Report, in support of both preventative interventions and the importance of listening to the voices of those with the closest experience of any health problem. The work done by the HOPE groups was cited as an example of good practice<sup>32</sup>.

Consistent with the Chief Medical Officer's position, and prompted by the publication of figures that showed that contemporary childhood mortality figures varied threefold across different UK local authorities, Dan Poulter, the Junior Minister responsible for Child Health, said that the government had already started a lot of good work. "We are heavily investing in support for mums, families, and children in the early years," he said. "We are training an extra 4200 health visitors by 2015, and 16,000 of the most vulnerable families will be helped by family nurses. But we know there is still much more to do."<sup>33</sup> It is clear that as initiatives such as these are implemented there needs to be vigilance to ensure that specific attention is given to the needs of women from minority ethnic backgrounds. There is still a persuasive case to target these women who experience the highest rates of infant mortality in the UK. That targeting needs to include a recognition of the strengths that can come from appointing additional health visitors and family nurses who themselves are from minority ethnic backgrounds. While it is clear from HOPE member's accounts that a major motivation for them was to effect the sorts of practical changes that would benefit others there was also a sense that being in the group offered personal benefits. The growth of self-confidence is clear in these accounts as are the

strengths gained from working with others who have had similar experiences. That strength is at times directed towards the past, acknowledging and reflecting on bereavement for example, and at times towards the future, group members report feeling able to develop new interests and take on new responsibilities. Both the benefits from group membership and the potential to benefit others has been recognised by women at both sites wanting to continue meeting as HOPE after the research ended and by the offer of support to continue by Public Health partners working on infant mortality in Leeds and by a charity, the National Childbirth Trust, in Bradford .

### **Bringing together research literature and personal accounts.**

The participatory research we report was located in a part of the UK with high levels of deprivation and with significant numbers of people from minority ethnic communities. Given the research reported above it is not a surprise that levels of infant mortality in the study areas are higher than national averages. We have noted that seeking to address health inequalities involves reconfiguring and targeting interventions to meet the needs of the more disadvantaged groups<sup>13</sup>, and that this recognition is evident in policy documents and pronouncements<sup>32,33</sup>. At a local level that reconfiguring might involve enhancing services, through professional training, health education and treatment. The overall message from HOPE is to listen to the voices of patients from the outset and to act speedily. This is a message of general relevance. But the particular slant brought to bear when it pertains to members of disadvantaged groups is that the listening has to overcome both entrenched professional reluctance to share decision making and societal assumptions that can be manifest in dismissive attitudes to disadvantaged groups, and sometimes to what is experienced as racism and blame.

The second theme in the research literature we reviewed is the one that looks at social capital. Here we considered both bonding with others similar to oneself and bridging to other groups, characteristically with different amounts of social power. We have seen how HOPE gave its members a sense of solidarity with others like themselves, it clearly exhibits an enhancement of bonding social capital. But that solidarity and the personal confidence it inspires also supported constructive contact with health professionals, academics and the media. We have seen how this contact led to changes locally and so can, with confidence, identify enhanced and effective bridging.

## **Conclusion.**

We began with a summary of all the structural, behavioural and service delivery factors impacting on infant health and the realisation that the common denominator in all of them was the social position of women<sup>3</sup>. Participatory methods are an empowering way of helping women at higher risk of infant death to have a voice in how health services are run and commissioned<sup>34</sup>. Thus, they offer a route to enhance the contribution of the structurally deprived while improving group member's self-confidence. This study has shown that groups like HOPE are feasible and can have a considerable impact on service development. If we want to address the social justice implications of inequalities in health we need to retain a redistributive politics at a national level, have a local level reconfiguration of service that privilege the sorts of services that will be of most value to the disadvantaged and have a planning regime built on listening to the voices of those most involved in any problem.

## **References**

1. Department of Health 2008. *Tackling Health Inequalities: 2007 Status Report on the Programme for Action*. London DH. .

- 2 D'Souza L, Garcia J. 2003 *Limiting the Impact of Poverty and Disadvantage on the Health and Well-being of Low-income Pregnant Women, New Mothers and Their Babies: Results of a Mapping Exercise*. Oxford, NPEU & Maternity Alliance.
- 3 Maher J and Macfarlane A. 2004 (Winter) Inequalities in infant mortality: trends by social class, registration status, mother's age and birthweight, England and Wales, 1976-2000. *Health Statistics Quarterly*.
- 4 See ONS series: Infant and perinatal mortality by social and biological factors  
[www.statistics.gov.uk](http://www.statistics.gov.uk)
- 5.The World Health Report 2005 <http://www.who.int/who/2005/annex/en/index.html> accessed 29.11.05.
- 6 Department of Health 2003.*Health Survey for England 2002* SO: London.
- 7.Kramer MS 1998 Socioeconomic determinants of intrauterine growth retardation *European Journal of Clinical Nutrition* 52 S1, S21-33.
- 8 Mwatsama M and Stewart L 2005 *Food Poverty and Health* Briefing Statement from the Faculty of Public Health, May.  
[www.fphm.org.uk/policy\\_communication/publications/briefing\\_statements/default.asp#f](http://www.fphm.org.uk/policy_communication/publications/briefing_statements/default.asp#f)
- 9 Graham H.2009.*Understanding Health Inequalities*.Maidenhead, Open University Press.
- 10.Austerberry H, Wiggins M., M. 2007. Taking a pro-choice perspective on promoting inclusion of teenage mothers: Lessons from an evaluation of the Sure Start Plus programme. *Critical Public Health* 17, 3-15.
- 11.Sosa R,Kennell J, Klaus M, Robertson S, Urrutia J. 1980. The effect of a supportive companion on perinatal problems, length of labor, and mother-infant interaction. *New England Journal of Medicine*, 303, 597-600.
12. Oakley A, Hickey D, Rigby A.S. 1994. Love or money? Social support, class inequality and the health of women and children. *European Journal of Public Health*, 4, 265-273.
13. Marmot, M.G., Adelstein, A.M. et al 1984. *Immigrant Mortality in England and Wales 1970-78*. HMSO, London.

- 14 Sheridan E, Wright J, Small N, Corry P, Oddie S, Whibley C, Petherick E, Malik T, Pawson N, McKinney P, Parslow R 2013. Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. *The Lancet* published online July 4<sup>th</sup> [http://dx.doi.org/10.1016/50140-6736\(13\)61132-0](http://dx.doi.org/10.1016/50140-6736(13)61132-0).
- 15 .Putnam R D 2000. *Bowling Alone*. New York. Simon and Schuster.
16. Pickett K , Wilkinson RG 2008. "People like us: Ethnic group density effects on health". *Ethnicity and Health*. 13 (4): 321-34.
17. Wilkinson, R.G. and Pickett, K. 2009. *The Spirit Level. Why more equal societies almost always do better*. London, Penguin
18. Siegrist J, Marmot M G 2006. *Social Inequalities in Health: New Evidence and Policy Implications*. Oxford, Oxford University Press.
19. Horwitz S M , Morgenstern H, Berkman L F. 1985. The impact of social stressors and social networks on pediatric medical care use. *Medical Care*, 23, 946-59.
20. Balaji A B, Claussen AH, Smith D C, Visser SN, Morales M J, Perou R. 2007. Social support networks and maternal mental health and well-being. *Journal of Women's Health*, 16, 1386-96.
21. Lai G, Lin N , Leung S YA, 1998. Network resources, contact resources, and status attainment. *Social Networks*, 20, 159-178.
22. Afridi, A. 2011. Social Networks: their role in addressing poverty. *Poverty and Ethnicity*. York: Joseph Rowntree Foundation.
- 23 McGlade M S, Saha S, Dahlstrom ME 2004. The Latina paradox: an opportunity for restructuring prenatal care delivery. *American Journal of Public Health*, 94, 2062-5.
- 24 Shaw R J, Pickett K E, Wilkinson R G. 2010. Ethnic density effects on birth outcomes and maternal smoking during pregnancy in the US linked birth and infant death data set. *American Journal of Public Health*, 100, 707-713.

- 25 Barnes, G. L. 2008. Perspectives of African-American women on infant mortality. *Social Work in Health Care*, 47, 293-305.
- 26 Redshaw M, Heikkila K . 2010. *Delivered with care: a national survey of women's experience of maternity care* . Oxford: National Perinatal Epidemiology Unit, University of Oxford.
- 27 Chevannes M. 2002. Issues in educating health professionals to meet the diverse needs of patients and other service users from ethnic minority groups. *Journal of Advanced Nursing*, 39, 290-298.
- 28 Essex H N, Pickett K E . 2008. Mothers without companionship during childbirth: an analysis within the Millennium Cohort Study.[Erratum appears in Birth. 2010 Mar;37(1):76]. *Birth*, 35, 266-76.
- 29 National Collaborating Centre for Womens's and Children's Health 2010. Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors. *Royal College of Obstetricians and Gynaecologists*.London.
- 30 Karl-Trummer, U. 2006. Prenatal courses as health promotion intervention for migrant/ethnic minority women: high efforts and good results, but low attendance. *Diversity in Health and Social Care*.
- 31 St Clair P A, Smeriglio V L , Alexander C S , Celentano D D 1989. Social network structure and prenatal care utilization. *Medical Care*, 27, 823-32.
32. Department of Health 2012. *Our children deserve better: prevention pays*. Annual Report of the Chief Medical Officer. London.
33. Hawkes N 2013. Childhood mortality varies threefold across different UK local authorities, report shows *BMJ* 2013;347:f6455
34. Salway S, Turner D, Mir G, Bostan B, Carter L, Skinner J, *et al.* (2013) "Towards equitable commissioning for our multiethnic society". *Health ServDeliv Res*;1(14).



